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AUTHOR Morrison, Gary N.; Morrison, Merrie B.
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ABSTRACT

The paper addresses stressors facing parents of emotionally disturbed adolescents and suggests ways that parents can be helped to battle "burnout." Ten stressors are identified: problems innate with the handicap, lack of progress and development, negative public opinion, pressures from spouse or other family members, pressures from members of parent support groups, loneliness, parental death, financial needs, lack of relief, and frustrations from interactions with professionals. Professionals are urged to assess parents' needs and to consider a variety of service options, including individual and/or group counseling, information services, respite care, and parent support groups. A sample program offering a flexible approach with a minimum amount of pressure and unreasonable demands on the parents is described. (CL)

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Burnout in Parents of Emotionally Disturbed Adolescents

Gary N. Morrison
Merrie B. Morrison

Interactions with the parents of handicapped children can often be trying experiences for many professionals--especially with those parents whose children have reached adolescence. We have all heard the professional who moans, "They just don't seem interested in their child. They won't cooperate with me, and I am trying to help their child!" Much of this "lack of cooperation" is simply due to a reaction by the parents to stressors that have been building up for years without relief. The professional who works with these children is able to take periodic vacations and/or change job-locations if the stress-level becomes a problem; and even then, some professionals complain of "burnout." They just do not feel able to handle the stress, and so either quit or, at the least, lose some of their sensitivity. The parent is not allowed to quit, and very rarely is allowed a vacation from the responsibility of raising a disabled child. It is only logical to assume that the level of stress felt by these parents will far surpass that felt by the professional. The constant, day-to-day battle that is fought by these parents can easily lead to a burnout situation that is often mistaken for lack of concern or cooperation (Boggs, 1978; Burke, 1978; Morton, 1978).

STRESSORS

Several of the stressors that are experienced by these parents will be discussed in this article. Care has been taken to try to approach each topic from the perspective of the

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parent. This is definitely not an exclusive list of topics, although the authors have attempted to identify the major stressors. Those stressors that will be discussed are

1) problems innate with the handicap
2) lack of progress/development
3) public opinion
4) pressures from spouse or other family members
5) pressures from "support groups"
6) loneliness
7) parental death
8) financial needs
9) lack of relief
10) dealing with professionals.

Problems innate with the handicap. This is an extremely variable category. The degree of stress felt by the parent is correlated to some extent by the degree and type of involvement that is present in the child. A child with no self-help skills who is totally dependent upon the parent and who also is unmanageable emotionally will cause quite a bit more strain than will the child who is self-sufficient and controllable. The personality of the parent is also a major factor. Some parents will be able to accept even major handicaps, while other parents can be devastated by what the professional would consider a minor problem (Webster, 1977). Care must be taken to evaluate the effect the specific handicapping condition has upon the particular

parent. Individual differences are so extensive that generalizations are useless and can often hamper, rather than aid, the intervention process.

Lack of progress/development. Anyone who is a parent knows how rewarding it is to watch his child grow and develop. The excitement experienced by parents who see their child stand alone for the first time and speak his first words is unparalleled by other experiences. This excitement is a natural reinforcement system which stimulates the parent to keep working with the child to achieve new skills (Heward, Dardig & Rossett, 1979). For many parents of emotionally disturbed children, there are very few rewards. Either the child does not progress at all, or the development is so slow that it takes an inordinate amount of effort, practice, and patience to achieve only partial progress. Is it any wonder that many parents feel frustrated and begin to question whether the level of progress is worth the effort? The real miracle is that so many parents are able to continue to work with such children, without knowing whether their efforts are effective. The rewards, if any, are few and far between, but many parents feel that when they do appear they are much sweeter and more cherished because they are so rare.

Public Opinion. The parents of disabled children "face the public" each and every time they leave their homes, and they must constantly battle the ignorance of the layman. Many people have incorrect assumptions about the cause of the condition and the extent of ability or disability of the child.

The parents are constantly faced with the decision of whether to try to educate the individuals or to just endure their inappropriate comments (Helsel, 1978). Many parents feel that it is necessary to appear well-adjusted and in control of the situation, regardless of how they actually feel (Bennett, 1978). They find themselves hesitant to go out unless they have the strength to handle the constant strain of confrontations, explanations, and maintenance of image. It is difficult to maintain this image, especially when they often receive cruel and abusive comments--comments that hurt even when the speaker is trying to be helpful. The parents easily become gun-shy and thus imagine a negative reaction from strangers when none is actually present. The axiom, "once burned, twice cautious," can be exemplified and multiplied by these parents.

Pressure from spouse or family members. The pressures that stem from opinions are not limited to those outside of the home. Parents are not a single unit. They are often considered to be a united front against the world, but this is often not the case. Many marriages are not able to withstand the added pressures that an emotionally disturbed child places upon them. Each parent has his or her own orientation and interpretation of the factors affecting the child. Overs and Healy (1973) stated the reason for this very well:

> Probably the single most important influence on a person's action or decision is the person's attitudes, beliefs, and values. As structuring and ordering devices, attitudes, beliefs, and

> values precede logical thinking and do not derive from logic or rationality. Therefore, the influence of basic attitudes, beliefs, and values on actions or decisions is primarily of an emotional, not an intellectual nature (p. 90).

If the parents are not able to reach a point of agreement on specific issues, then there is a constant added strain that affects the entire family.

Pressures come not only from the spouse, but from the siblings and members of the extended family, who also feel that they should have input into the events that affect the child, as they, themselves, are also affected by these events. They must be led to understand the important issues so that they can have enlightened interaction with the child and parents (Heward, Dardig, & Rossell, 1979). The pressures that these family members can place upon the parents are more severe than those of outsiders because of the increased emotional significance they play in the parents' decision-making processes.

Pressure from "support groups". A parent support group should be formed for the purpose of providing an information-source for parents, providing social interaction with others who can understand the stresses faced by the parents, for allowing the parents to see that they are not alone in their struggle, for providing a list of alternative methods of interaction with the child, and as a central location for child-advocacy activities. These issues will be discussed in a later section. There is one problem with parent support-groups, however, that has not been adequately

recognized: they can increase, rather than decrease, the pressures that are on the parent. This happens when the parents are made to feel that they are not being good parents unless they are actively participating in such groups. Many groups pressure parents to "volunteer to work for their child" in activities that require a lot of time and energy which the parents might not have available (Bennett, 1978). The unspoken assumption is that if the parents do not run to fulfill the request then they don't really care for their child. It has been shown that many parents are already stressed to the limit of their capacities. The added pressure is very unwarranted and can lead to the withdrawal of parents from the group altogether. This can be avoided if it is remembered that the purpose of the group is to support the parent, <u>not</u> for the parent to support the group.

<u>Loneliness</u>. Many parents have expressed the fact that they have a feeling of loneliness (Sarason & Doris, 1979). This is more evident in the parents of adolescent emotionally disturbed children (Bennett, 1979). When a child is born, parents understand that there will be several years when their social life will depend upon the availability of babysitters, or upon those activities which can include the child. They expect to be able to stop having to arrange for child-care when the child reaches adolescence, and consequently they can more easily increase their social interactions outside the home. Parents of emotionally disturbed adolescents must

continue to provide for child-care if they are able to get out of the house. Child-care for the emotionally disturbed child is difficult or impossible when the child is young, and it becomes increasingly difficult as the child gets older. Thus, the parents find themselves cut off from social interactions with other adults (Morton, 1978). These parents also have a multitude of problems and concerns that are different from those of parents of normal children. Things of seemingly serious concern to parents of normal children can be viewed as minor to parents who must deal with a very disruptive child. This can put the parents into different planes of reference and make interaction between them more difficult. It can, indeed, lead to the development of a feeling of being cut off and alone.

Parental death. Parents try to provide for their children in the event of their own deaths. This includes insurance, possibly a burial plan, and maybe a relative who agrees to take care of the children until they reach legal age. Parents do not expect to die before their children are self-supporting, and statistically, they are supported in these expectations. The parents of the severely disturbed child must face the knowledge that they will probably die before their child does, and that the child will probably never be able to be self-supporting (Sarason & Doris, 1979). Many of these children require an extensive amount of care for their entire lives. It is one thing to ask a person to take

on the responsibility of a normal child for five to ten years; it is an entirely different matter to ask that person to take on the responsibility of a disturbed person for twenty to forty years! The situation is further complicated by the fact that it is difficult, if not impossible, to use the present legal system to try to insure that the child's care is consistent with the standards set by the parents. This issue forces the parents of disturbed children to recognize their own mortality far earlier than those parents of normal children (Sarason & Doris, 1979). The frustrations met in trying to make adequate provisions for the child are definitely added stressors.

Financial needs. Raising normal children is an expensive process. Add to this baseline the different special costs that are inherent in caring for an emotionally disturbed child, throw in the bureaucratic red tape that is normally required if financial assistance is to be obtained for the child, and don't forget to include the economic and political fluctuations that effect the availability of funds. This recipe makes a very volatile mixture, which can increase the stress-load of the parent just as gasoline can fuel a fire. With enough fuel, an explosion can result--or the fire uses up available resources and burns out.

Lack of relief. All of the stressors thus far have had one common theme: they are constant, day-after-day problems that are never solved (Morton, 1978). As was

previously stated, these parents cannot stop being parents of an emotionally disturbed child. Adequate child-care is very rare and must be saved for necessary occasions, such as working hours. Many parents state that they feel they have lost their identities as persons (Bennett, 1978). They become Joe's mother or Sally's father. Their whole existence begins to revolve around the continuous battle with the stressors. They must be available to solve one crisis after another, with little reward, and no relief. They are not allowed to step out of the situation even long enough to regroup and rearm their defenses. Thus parents of adolescent, emotionally disturbed children often have a haggard-tired look that portrays their exhaustion (Morton, 1978). These parents need some time out. They need to have some time for themselves with which to find the person who is hidden behind the responsibilities. A few short weeks of total freedom from these responsibilities can make a major difference in the capabilities of the parent. Programs that work with these parents and children need to recognize this problem and make provisions accordingly. This issue will be discussed in more detail later in the paper.

Dealing with professionals. The final topic was reserved until last because it can be the most damaging of any of the stressors listed. The most often-voiced complaint from parents is the frustration they feel when trying to interact with those who will influence what intervention-methods are to be used with their child (Blatt, 1978; Helsel,

1978; Roos, 1978; Sarason & Doris, 1979; Schulz, 1978). Of course, not every professional is frustrating to the parent, but unfortunately, most parents state that these are the exceptions rather than the rule.

There are several areas in which this frustration can occur. First, the parent comes to the professional needing clear, concise information, presented in a manner that the parent can understand (Roos, 1978). Instead, they either do not get any information or the information that they do get is explained in highly technical terms. Either way, the parent is still in the dark about exactly what the problem is. Also, many professionals hesitate to say that they do not know everything about the problem. They feel that this will decrease the confidence of the parents. This is a mistake, as a wrong guess can have devastating consequences for both the parents and the child.

Once they have a baseline of information about their child's condition, the parents need a list of the available options for intervention-methods, with non-biased recommendations as to which option would be most appropriate. Too often, the parents are not given a choice by the professional. They are told, "This is what we are going to do," as though the parents had no choice (Roos, 1978). There are <u>always</u> choices, and it is up to the parents to make informed decisions about what happens to their child.

Third, the parent is the person who must live with the child on a day-to-day basis, and thus is the one most affected by, and influential in, the changes that occur in

the child. Many professionals treat the child as though he were isolated from the parents; others act as though the parentswere totally responsible for the child's problems. Either orientation is wrong. Although some problems can be traced to the home-environment, others, such as autism, definitely are not. However, the child is in the home, and the intervention-methods used are definitely influenced by, and, in turn, influence the parent. If the particular treatment suggested cannot fit the particular situation, it will not be implemented properly. Lack of recognition of this fact can destroy the effectiveness of any treatment program.

Finally, and most important, the parent has a vast store of information that can be invaluable to the professional in assessing the child. This is true of the initial diagnosis, and of the continual progress of the child. Far too often, the parents are treated as though their input was worthless. Even those parents who are also professionals have stated that they have been treated as though they cannot be objective and report valid observations when discussing their own child. Colleagues who request the parent's professional expertise for another child will sometimes push aside the same information when it is applied to the child of the professional parent (Roos, 1978; Turnbull, A., 1978). What is this need of many professionals to totally disregard the information that parents have to offer? Is it conceit, superiority, or self-defense? The authors are not trying to insult any professional reader. Many times, the professionals

do not realize the extent to which they are guilty of this behavior, and, to some degree, all of us are. If the professionals can put themselves into the parent's place, listen to themselves from the perspective of the parent, perhaps videotape some of their interviews and critically assess themselves, then they can discover how guilty or innocent they are of this crime, and try to adjust their behavior accordingly.

The role of the professional as a stressor is at once the easiest and the most difficult to alleviate. Individually, we <u>can</u> each work to view our interactions with parents from their perspective and try to meet their needs. This would drastically reduce the stresses felt by the parent. We <u>cannot</u> control the behavior of the other professionals with whom the parents must interact. Also, there are many bureaucratic rules and regulations of the institutions represented by the professionals which might cause frustration. We <u>can</u> let the parents know that we understand their feelings of frustration, and try to assist them in dealing with them. The next section of this article will discuss various methods of intervention with parents to help them reduce stress.

ASSESSING PARENT NEEDS

Combatting parent burnout is a necessary part of any intervention program for older emotionally disturbed children. Parents who have lived with these stresses for years often reach a point where they feel that they cannot go on. When the parent of an emotionally disturbed child says, "but I

have my own life to lead," what he/she is often saying is that the stress of raising the child is becoming too much (Reid, 1971). This is a cry for help that must be addressed in order to maintain family stability.

The question is, how can we best deliver the needed services to the parents? Past attempts have assumed that all parents need all of the services that professionals have to offer (Alexander, Kroth, Simpson, & Poppelreiter, 1982). Slowly, professionals are coming to realize that the needs of parents vary at different stages in the child's educational life (Coletta, 1975) and thus no one approach can address all needs of all parents. Professionals have to analyze the needs and skills of the parents and attempt to individualize the services as much as possible.

This means that professionals must be flexible in the planning of an assistance program. It is true that the needs of the children are great, but the needs of the family are greater (Stewart, 1978) and can only be met by offering a variety of services that require different levels of commitment from the parents.

SERVICE OPTIONS

The most common service options offered to parents are individual and/or group counseling (Paul & Epanchin, 1982). There are some parents who need intensive individual counseling to help them deal with the problems of everyday life. There are other families that will greatly benefit from some

form of group therapy. This can be especially true in parents of secondary-age emotionally disturbed children who have had to deal with the problems associated with raising such a child day in and day out, year after year.

Individual counseling and family therapy are excellent intervention methods, and should be offered to parents who need this type of help. The authors, however, believe that the needs of many parents can be met through other, less intensive means. This assumption is based on the belief that parents have different needs at different times in their child's life and, thus, their availability for involvement will vary from time to time. If only these two options are available, professionals are not adapting their services to the needs of the parents.

For example, one overwhelming need of some parents is respite from their emotionally disturbed child (Alexander, et al., 1982). This need is often viewed by the community, and by some professionals, as a rejection of the child. Respite is an effective means of lessening the constant stress of parenting such a child, and can be essential for the mental health of the family. A summer camp, special summer sessions, or a short-term institutionalization can allow parents time to rest, regroup, and strengthen strained family relationships.

Professionals should not only help arrange for some type of respite, but need to assist parents in dealing with any guilt that might arise from the decision. Very often, all that is required is for someone to say that he understands

the parent's reasoning and agree that the time can be beneficial to both the parents and the child. This will help parents feel more secure in the decision and allow them to use the time for stress-reduction rather than increasing feelings of guilt and anguish.

Another critical need of parents is to be provided with accurate, understandable information concerning their child's condition and the intervention program being used. Conner, Riesalem, and Cruickshank (1971) asked parents of the handicapped what service they most needed from professionals. The overwhelming majority said that their greatest need was for someone to sit down with them and explain, in terms they could understand, their child's disability, what they could expect in the future, what was being done for their child, and how they could help. When people are informed, and have some idea of what to expect, stress is reduced and the ability to cope with the future is expanded.

The school would be the agency in the best position to carry out this service. They have access to complete information on the child: medical, psychological, and educational. Also, providing this type of service would help to raise the parent's respect for, and confidence in, the school. Many parents, especially those of adolescents, have a long history of negative contacts with the school, and therefore view the school as part of the problem rather than part of the solution (Alexander, et al., 1982). An excellent example of this is a statement made by the mother of a secondary age

autistic child that a phone ringing during school hours sent a chill through her body, wondering what the child had done now (Jones, 1980). If parents could come to view the school as a source which they could turn to for information and support, they would feel less alone and more in control of their situation.

Another way of helping the parents deal with the stress associated with the rearing of an emotionally disturbed child is the parent support-group. This is not a group-counseling situation, but an association of parents who meet to discuss common concerns and exchange views on raising their children.

One great benefit of such an organization is that meeting with other parents who have similar problems helps to lessen the feeling that one is alone in facing such problems. Often, the simple knowledge that others share in this unusual life-situation relieves tension and makes the parent's existence a little easier.

A parent-group also gives the parents of older children a chance to give assistance to parents of the younger emotionally disturbed. They can give assistance in child-rearing techniques and give the parents of elementary-age children information on who to turn to for support in the secondary school, as well as what pitfalls to avoid. An extra bonus of this situation is that the parents of the older children usually find it refreshing and an ego-boost to help others, rather than receive help for a change.

A SAMPLE PROGRAM

The senior author has been working with a group of parents to establish such a support-group, and the services that the parents are interested in provide an excellent example of the types of activities parents need. The group is being formed by parents for parents, so the services being included represent what they feel is necessary, rather than what professionals feel is necessary.

One of the first things that the parents want is to develop contacts with those in the community who can help them become better parents. They are interested in receiving information from an attorney on will and estate planning for their child. They also want to find out about respite services, and how to qualify for financial services to help defray any costs such services might require.

Along the same lines as respite services is the desire to set up a baby-sitter service. The parents are very interested in finding people who are willing to sit with their children so that they can get some time together. One mother said that she felt she could deal with anything, if only she and her husband could go out to dinner or a movie once in a while. We often forget how difficult it is for these parents to get a sitter and how refreshing a night out can be.

Counseling services, both group and individual, were suggested, but it is interesting to note that this was one of the last items considered. Formal counseling can help, and

for some it is a necessity, and the parents recognize this. They seem to feel, however, that counseling alone will be of little help to them.

By being flexible and allowing the parents to make the major decisions in the planning of the group, we hope to form an organization truly responsive to their needs. Care is being taken to prevent parents from feeling pressured to attend meetings or give more time to the organization than they feel comfortable with. The idea is to allow parents to decide on the level of involvement most beneficial to them and to allow them to change that level as their life-situation changes.

This last point--keeping the pressure off--is perhaps the most overlooked aspect of professional services. The goal of any assistance program should be stress-reduction, and this can only be accomplished by a concerted effort on the part of professionals not to add to the problem by making unreasonable demands on people who are already stretched to their limit of tolerance. When this is added to a program of flexible services, designed to meet individual needs, we will have done a great deal to alleviate parent burnout.

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